National Center on Birth Defects And Developmental Disabilities Committee Assignments September 25, 2003 Brainstorming Session

Education Advocacy Committee and Communications Committee

- Market/spread the word about our purpose and objectives. Educate Capitol Hill.
- It is important to educate congress, but it is equally important to educate our **own** state Health Departments.

Education Advocacy Committee Communications/Membership Committee Programs & Policy Committee

- Spread the word that the <u>expense of not preventing</u> birth defects and developmental diseases is a strain on society and that our focus should also be on preventing secondary complications, not just on preventing childhood disabilities.
- When approaching Capitol Hill, take people with disabilities along, who can model as <u>success stories</u> as an example of what <u>can</u> be accomplished.
- Educate and train legislatures to ensure those from diverse communities have access to health care.

Programs and Policy Committee

- We need to focus also on <u>Disability Management</u>. Spread the word to families, Capitol Hill, and society as a whole.
- Discuss and identify strategies about what <u>supportive environments</u> can do to get people with disabilities into the workforce."
- Determine where there are gaps and expand the programs

• Early intervention is important however the focus needs to include those with diseases and disabilities that follow.

Education Advocacy Committee

- Conduct briefings to those on Capitol Hill and ask for sponsorship.
- Involve the appropriations folks in our efforts.
- Hold briefings on Capitol Hill, sponsored by different centers/groups to provide information.
- <u>Provide information</u> to congress about the costs, and what is being done. (The Coalition for Childrens Health has put together a pamphlet, which may be used as a model).

Communications/Membership Committee

- •Broaden our <u>list</u> of invitees to meetings.
- <u>Use List-serve</u> to get the word out.
- <u>Develop a unified website</u> for more effective marketing and sharing of information.
- Collaborate and provide input into information for presenting at 2004 Conference.
- How do we get the respect?

Communications/Membership Committee Programs and Policy Committee

- Develop a matrix to determine commonalities to gain more collaboration.
- Identify and provide the numbers (by community) on who is affected

Communications/Membership Committee (assisted by the Education Advocacy Committee and the Programs & Policy Committee

- Develop a list of "How can I help you" questions, for posting on the website.
- The "One Word Against Cancer" initiative has been effective, and might be used as a model.
- Conduct Awareness campaigns, with the emphasis on Early Prevention. (example: Autism Campaign).
- Spread the word that "Early diagnoses, and Early Intervention will ultimately save health care dollars".

Communications/Membership Committee

- Attend marches, conferences (events where high numbers of individuals will be present) and spread the word, providing literature, pamphlets, etc.
- <u>Talk</u> to the "Babyboomers" and <u>reach</u> out to AARP.
- Coerce national television networks to give <u>free airtime as a public service</u>.
- Task the Communications committee to do the Public Relations marketing as their first tasking.
- Get the Key <u>stakeholders</u> <u>involved</u>.
- Have the Partners Group participate in Public Health Briefings (setting up display booths with flyers, etc.) to spread the word.
- The Mission needs to be explained and <u>marketed internally</u>, not just externally
- Determine who we are reaching and go from there.

Communications/Membership Committee Programs & Policy Committee

- Conduct a campaign, studying stereotypes tied to persons with disabilities. The objective is to do away with the negative stigma.
- Look at and spread the word about the Impact on the Family.

Education Advocacy Committee (assisted by Communications/Membership and Programs & Policy Committees)

- How do we get the resources we need?
- Remind congress that the money is being spent, it's just being spent in the wrong places.

Programs & Policy Committee assisted by Education Advocacy and Communications/Membership Committees

• Identify programs that work and spread the word about what contributed to the success.

? Having the Name tied to the mission may get certain agencies/companies to buy in.